



The Princess Royal Trust
for Carers

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TOUGH BREAKS FOR CARERS

*A report on Primary Care Trusts and delivery of the National Carers' Strategy
March 2010*

Our findings

Our report *No breaks for carers* found that only 23% of the £50m given to Primary Care Trusts (PCTs) in 2009/10 to increase their services for carers was actually used for this purpose. Many carers felt that money which had been announced by Ministers to parliament had not reached them. Government action to address this problem was limited. This report updates the picture with new data on PCTs' budgets for 2010/11, during which period they have been allocated a further £100m to increase their services for carers.

Our findings:

- PCTs plan to spend only 26% of the £100m to increase services for carers – a small improvement on last year's situation, despite considerable public scrutiny.
- A significant proportion of the money that is being spent could be doubled-counted against the money allocated for other government strategies.
- In many cases, some of the most vulnerable and elderly carers are excluded from new provision.
- 25% of PCTs plan to reduce spending on services for carers, despite the extra resources although in just under half of these cases, the PCT would still be spending relatively high amounts on carers' services.
- A small number of PCTs continue to provide no services at all for carers.
- This picture is reflected across a number of policy areas: up to £1bn may not have reached its intended recipients.

So, of the £150m committed over 2009-11, only approximately £37.5m will be used to increase support for carers. The rest has disappeared into unnamed NHS budgets.

In responding to our original report, the Government stated that all PCTs had to record their performance against a carer's performance indicator (as part of the NHS Vital Signs framework). Our survey found that two-thirds still did not record this information.

There were examples of PCTs who have chosen to significantly increase their services for carers, such as NHS Heart of Birmingham who also offer a wide range of services. The

Government should attempt to share the benefits that such PCTs have found with all PCTs and encourage learning among PCTs.

Worryingly, the problems affecting implementation of the Carers' Strategy appear to be replicated with implementation of the Child Health, End of Life Care and Dementia strategies. These four strategies represent Government announcements of nearly £1bn in new spending and it is hard to establish how this £1bn has been used in reality.

Minister for Care Services, Phil Hope MP, recently pledged to “personally hold PCTs to account”. We welcome this very positive announcement. Clearly, the Minister must act immediately or the Government will have failed on its pledge to carers.

Who are carers?

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

Carers do not get the support that they need:

- More than half of carers have given up work to careⁱ
- On average, carers retire eight years earlyⁱⁱ
- More than 80% of carers say that their caring role has damaged their healthⁱⁱⁱ
- 75% of carers have reached breaking point whilst caring^{iv}

Detailed findings

Our investigation found that PCTs plan to use only 26% of the £100m given for 2010/11 to increase services for carers. This is a very small improvement on the proportion of the allocation given for 2009/10. This also included 25% reducing the amount they were spending on carers' services despite the £100m increase and a few apparently still not funding any carers' services.

Many PCTs advised that they would not set budgets until late March. PCTs have known about this extra money since June 2008 and the best committed their spending at an early opportunity, reflecting the high priority accorded those few accorded to carers. Funding uncertainty makes it very hard for charities providing support services to plan their work.

We are particularly concerned that the reported spending of carer's strategy funding by some PCTs may actually represent their spending to deliver other government strategies, such as the Child Health Strategy *Healthy lives, brighter futures*, which announced £340m for disabled

children's services, including short breaks. The strategies have similar aims, and the people they are intended to benefit may overlap, but the government has clearly identified separate pots of funding for PCTs to deliver the strategies.

For example, NHS North Yorkshire and York will be the biggest spender on breaks for carers, £1,916,000, but this will only be available to the parents of disabled children. In other cases, a different group of carers appeared to be supported at the expense of all others. NHS Westminster plan to spend £1.4m on breaks for carers of people with learning disabilities (76% of their total spend).

While we do not dispute the fact that funding for breaks for parents of disabled children is vital, this indicates that these areas may be reporting spend under the Child Health Strategy as spend under the Carers' Strategy. The difficulty here is that a lack of robust monitoring arrangements for both strategies means it is hugely challenging to determine whether the local allocations are appropriate or not.

Similarly, some PCTs reported their planned spend on dementia and end of life care services in their response to us. In 2009-11, the End of Life Care Strategy made £286m available to PCTs and the Dementia Strategy £150m.

We found that two-thirds of PCTs advised that they did not record information on their performance against the carers' performance indicator within Vital Signs. Some of them referred us to their local authority, indicating that they did not see collection of this information as their role.

A discord: national announcements and local delivery

Our findings and research by other charities show that nearly £1bn has been given to the NHS without Government being able to show how much will be spent on what was announced by Ministers and intended by parliament.

Research conducted by other charities on these strategies found similar problems to those we have uncovered regarding implementation of the Carers' Strategy. Help the Hospices found that 26 out of 28 PCTs surveyed had either been unable to identify any additional funding to support the implementation of the End of Life Care Strategy, or had taken a conscious decision to use the additional resources on other priorities.

The Every Disabled Child Matters (EDCM) campaign has found that PCTs are struggling to identify the funding allocated via the Child Health Strategy, with some PCT commissioners commenting that it has been difficult to convince their finance chiefs that the additional funding is in the budget at all. Research by EDCM also found that the majority of PCTs failed



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to submit a statement on disabled children to their SHA by the 30th September 2009 deadline imposed by government.

Whilst most have now submitted a statement, only a minority have included any information on their current or planned financial investment for disabled children in the four key service areas they are expected to invest in: short breaks, community equipment, wheelchairs and children's palliative care.

The National Audit Office (NAO) criticised elements of the implementation of the Dementia Strategy saying that it had not been given the levers or urgency needed to deliver a national priority.^v

There is a systemic failure in the way that Government attempts to implement or monitor the progress of national strategies. A dozen leading charities asked Secretary of State Andy Burnham MP to meet to share findings and discuss solutions, but this offer was not accepted.

Problems associated with these four strategies are in contrast to the implementation of the Stroke Strategy which was positively reported on by the NAO^{vi}. There are two crucial differences that account for this: funding to implement the Stroke Strategy is clearly identifiable within budgets and ring-fenced; the performance indicator for PCTs in relation to the Stroke Strategy is a Tier 1 priority for the NHS, which makes it compulsory.

Spreading good practice in the NHS

As with last year's report *No breaks for carer*, we did find encouraging examples where PCTs are investing substantially in commissioning a broad range of services specifically for carers. The publication of The National Carers' Strategy has undoubtedly raised the profile of carers with the public and within the NHS. We must encourage all PCTs to replicate in the outstanding commissioning practice of those high performers. We hope to work with the government on achieving this goal.

NHS Heart of Birmingham was not one of the biggest spenders on carers' services before the Carers' Strategy was launched although was investing significant sums. However, it has taken the evidence in the Carers' Strategy and increased its spending on carers in 2009/10 by £350,000 and plans to increase spending again by £500,000 in 2010/11. This increase equates to over three-quarters of its share of the total £150m allocated over 2009-11.

Impressively, they have also commissioned new services whilst expanding the capacity of existing services to ensure a wide range of support for carers. They have planned this jointly with the local authority and sought feedback from carers on what services they value and



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would like. The PCT places particular emphasis on meeting the health related needs of carers which the local authority is not able to meet through its funding.

Services include the availability of grants to help with purchasing equipment, travel, outings and the opportunity to access replacement care for the cared for to enable the carer to take a break. Training and health checks for carers are also offered, as well as transport costs for carers to attend GP and hospital appointments.

West Sussex also plans to invest £95,000 to provide carers' support workers in all GP practices in West Sussex. This a joint project with the local authority. The table below illustrates the dramatic rise that can occur in carer identification rates with dedicated workers supporting GPs. Early identification can help carers avoid a physical or mental breakdown themselves. This evidence was collected by our Carers' Centre covering Harrogate, Craven and Airedale:^{vii}

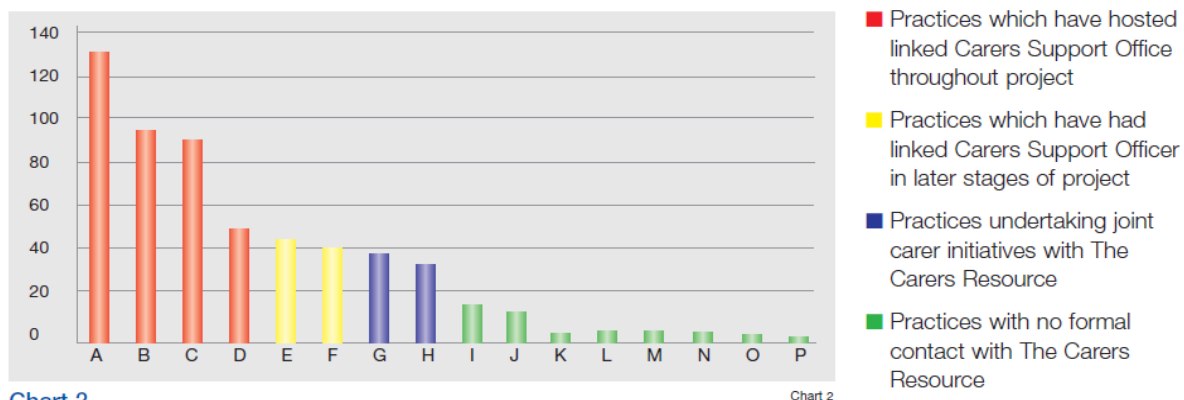


Chart 2
The Carers Resource carers registered at Airedale practices

West Sussex plan to invest £283,000 to support carers of people with mental health problems. Carers of mental health problems are less likely to be identified and therefore access support. The lack of support in addition to the fear of stigma can increase the difficulty in managing their caring role.

The same problems are probably even more evident in relation to carers of people who misuse substances. A recent report by the UK Drugs Policy Commission which we advised on highlighted the lack of support for such carers^{viii}. NHS Cornwall & Isles of Scilly are funding new services in this area. NHS Wandsworth fund specific services for carers of people misusing substances or with mental ill health.



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A call to action

Our two reports on PCT spending of the £150m allocated by Government to support carers indicate a failure by the NHS to implement fully the National Carers' Strategy and to prioritise carers. £112.5m promised to carers by the NHS will be used on other areas of work.

Carers do not know what PCTs have done with the money nor can they judge on an 'outcomes' based measurement how well their PCT is doing making local democracy impossible. To address this, the following actions are required:

- Central government must publicise the importance of supporting carers to the NHS.
- Central government, regional Strategic Health Authorities and the Care Quality Commission must hold the NHS to account for its treatment of carers.
- The NHS needs a greater understanding of the health and economic cases for carer support, backed up by cost-benefit analysis of carer support interventions.
- In future editions of the NHS Operating Framework and NHS Vital Signs, performance on carers support, should be given Tier 1 or Tier 2 priority. It should not remain at Tier 3 as an optional area of practice.

This report highlights systemic problems facing the implementation of a number of government strategies. To address these, government must:

- Announce new monies only when such announcements are accompanied by clear procedures for monitoring the spending of those funds and holding local bodies to account.
- National Strategies should routinely be accompanied by prominence in the NHS Operating Framework and accompanied by a Tier 1 or 2 NHS Vital Sign performance indicator, as has happened successfully with the Stroke Strategy.
- Focus clear communication to the NHS of desired outcomes, rather than on the use of national spending announcements, which are an ineffective and potentially misleading approach given the devolved nature of NHS management.

The National Carers' Strategy remains unfinished business. The new money has not yet been spent on carers and there is no new funding guaranteed from 2011-12 onwards. In an increasingly tough economic climate, whatever government is in power will have much work to do to ensure that the early momentum of the National Carers' Strategy is not entirely lost. The Third Sector and carers themselves will be only too happy to assist in achieving the strapline of the vision of the National Carers' Strategy: that by 2018, carers would experience *"A caring system on your side. A life of your own."*



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Endorsement

This report has been endorsed by the following organisations:

Counsel & Care, Help the Hospices, Macmillan, Motor Neurone Disease Association, MS Society, Parkinson’s Disease Society, Rethink and Voluntary Organisations Disability Group which represents forty organisations.

rethink



counsel + care
for older people, their families and carers

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Appendix: The relevant government policies

HM Government’s National Carers’ Strategy contained a commitment that English Primary Care Trusts (PCTs) would be given new money to provide breaks for carers and the Prime Minister highlighted this pledge as a key policy in his preface:

“We are taking immediate action to double our support for respite care over the next two years with an additional £150 million of new funding.”^{ix}

The following paragraphs from the National Carers’ Strategy gave more detail about the policy^x:

3.12 The money will be allocated to PCTs, who will be required to work with their local authority partners to publish joint plans – as part of the Joint Strategic needs assessment process (see Chapter 7) – for the provision of breaks. These plans will be published following a local consultation with relevant parties, including the third sector and carers themselves. Setting out a strategy for improving quality and choice, the plans will take account of both the new money and the existing money provided to local authorities for planned breaks through the Carers Grant.

3.14 This additional funding significantly increases our investment in direct support for carers, and we expect that it will provide a wide range of services in response to their specific needs.

Following our first report, Secretary of State Andy Burnham MP appeared to give encouraging signs advising Parliament that:

“I have been considering whether we can strengthen the language relating to that commitment as part of this year’s operating framework” and “we included that funding



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requirement [£50m for carers] in the operating framework of the NHS, and I assure him that we will be repeating it when the framework for next year is published.”^{xi}

The NHS Operating Framework, published two days after this statement did not refer to the Carers’ Strategy or the extra funding for 2010/11.^{xii} Furthermore, supporting carers remained a Tier 3 NHS priority, which means that PCTs plans for carer support are entirely at their own discretion.

The outcome measurements for PCTs are in a framework called NHS Vital Signs, which is divided into three tiers with Tier 1 being the most important and the third tier being of lowest importance. The outcome measurement for carers is in Tier 3 and is the following:

Proportion of carers receiving a ‘carer’s break’ or a specific service for carers as a percentage of clients receiving community-based services

In a letter to us, the government stated that:

“PCTs have been asked to publish their performance against all of the Vital Signs, regardless of whether they have chosen an area for improvement. This will include their performance during 2008/09 against the indicator on carers’ support. These reports will give local partners, stakeholders and members of the community an opportunity to consider the provision of support to carers and inform the priorities selected by PCTs and their partners for action during 2010/11.”^{xiii}

The Princess Royal Trust for Carers and Crossroads Care were contributing authors for government-funded guidance, *Commissioning for Carers*^{xiv} which advises health and social care commissioners about the range of services needed to help carers achieve the five outcomes set out in the vision of National Carers’ Strategy. It includes advice on commissioning breaks services.

Appendix: Methodology

We submitted a set of questions in February 2010 under the Freedom of Information Act to 151 PCTs asking for their spending intentions regarding carers in 2010/11. This and other questions would allow us to calculate what proportion of the £100m they were using to increase services for carers. We also sought to gather PCT performance in relation to the carers’ indicator in the NHS Vital Sign framework using the same method.

The National Carers’ Strategy pledged to increase support services for carers, so our data looks at whether the new money has been used to increase services, rather than simply maintaining existing services.



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- ⁱ *Real change, not short change: Time to deliver for carers*. Carers UK, 2007
- ⁱⁱ *Real change, not short change: Time to deliver for carers*. Carers UK, 2007
- ⁱⁱⁱ General Household Survey, 2000
- ^{iv} Carers Week Survey, 3000 carers, June 2009
- ^v *Improving dementia services in England – an interim report*, National Audit Office, Jan 2010
- ^{viii} *The Department of Health; Progress in improve stroke care*, National Audit Office, Feb 2010
- ^{vii} Pg. 24, *Putting People First without putting carers second*, The Princess Royal Trust for Carers & Crossroads Care, 2009
- ^{viii} *Family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses*, UK Drugs Policy Commission, Nov 2009
- ^{ix} Pg. 4, *Carers at the heart of 21st century families and communities*, HM Government, June 2008
- ^x Pgs 74-75, *Ibid*
- ^{xi} 14 Dec 2009, <http://www.publications.parliament.uk/pa/cm200910/cmhansrd/cm091214/debtext/91214-0008.htm>
- ^{xii} Para 2.48, Pg. 22, *The Operating framework for 2010/11 for the NHS in England*, Department of Health, 2009
- ^{xiii} <http://www.number10.gov.uk/Page21841>
- ^{xiv} *Commissioning for Carers*, The Department of Health, 2009